



## **When Your Loved One has Parkinson's Disease: 6 Tips for Coping with Changes**

By Cassandra Van Dyck

*"I now realize that this is a marathon, not a sprint, and that we need tools to help us cope with what is ahead."* – Parkinson's caregiver

A diagnosis of Parkinson's disease is tough for the person diagnosed and for their loved ones. There is no cure for the degenerative disorder of the central nervous system, that mainly effects the motor system, though the symptoms and progression can vary greatly from person to person. For the care partner of someone with PD, coping with the changes that come with the disease can be challenging. Care partners may be expecting physical changes in their loved one, but may not be prepared for cognitive changes or other symptoms such as fatigue, constipation and sleep problems which can interfere with daily life. In advanced stages, the role of a care partner for someone with PD can be physically demanding as well, as they increasingly have to assist their loved one with physical tasks such as getting dressed, eating, and bathing. The evolution of PD is unpredictable - physical and cognitive changes can happen slowly over time. Coping with grief and loss as PD progresses can feel overwhelming.

Are you or is someone you know caring for someone with PD? Here are some tips to help you cope with the changes that your loved one may go through.

Work with your health care team.

If your loved one has Parkinson's, chances are you already have relationships with many health care professionals. Knowing and building your team may help you and your loved one manage symptoms and changes and can improve quality of life. Try not to rely on one professional to

build your team! Sometimes both of you will have to do a bit of work to access services. A movement disorders specialist, speech-language pathologist, physical therapist, occupational therapist, and social worker are examples of professionals who are great allies for your journey.

Stay up to date with the latest research and treatment strategies.

Jane Fonda found out her partner, Richard, had PD on their first date. She didn't think much of it until they fell in love. "Richard, if you don't take your disease seriously and become an expert in it so you know exactly what your options are, I'm not hanging around," she told him. He did, and they work together to manage the symptoms and the ups and downs of PD.

The more you know, the better equipped you will be to handle changes and create strategies to cope with symptoms as they come up. If you read or hear about a treatment strategy you were not familiar with before, talk to someone from your health care team about it! The Pain Centre at Saint Paul's Hospital, The Michael J. Fox Foundation for Parkinson's Research, and research by Dr. James Beck are great places to start.

### **Keep asking questions until you understand the answers.**

"UNDERSTAND – The disease, the roles of the various health care professionals and the treatments available. Keep a drug diary. Record and research medication responses. Keep a binder of information on PD." – Bob Kuhn

With the increasing demand on BC's health care system, appointments can often feel rushed as doctors endeavour to see as many patients as possible during operating hours. Your health care professional may explain something and think you understand, while you may leave feeling confused. Don't be afraid to ask questions until you understand the answers. Try repeating back to the professional what you've heard to make sure you're leaving with all the information you can get. If you're not sure how to respond, try starting with, "I think what I hear you saying is..." If you are given treatment options such as prescriptions or surgery, ask for details on the benefits, side effects, and treatment options. Getting clarification will help you feel confident in providing care and accessing the services you may need to move forward.

### **Know your supports and services. Access them.**

"You can't do it alone. Lean on your family and friends. Make use of non-profit volunteers and government agencies. Look for and accept all the help you can get." – Maggy Hurchalla, sister of Janet Reno

With the increasing number (and awareness!) of caregivers in Canada, there are a growing number of services available. Network groups, one-on-one support, respite services and information packages are just some of the resources available. The Parkinson Society of BC ([parkinson.bc.ca](http://parkinson.bc.ca)) is a fantastic resource. If you need a break, consider looking in to local respite care, such as Cedarview Lodge in North Vancouver.

### **Make friends with another care partner.**

“Lots of people want to ride with you in the limo, but what you want is someone who will take the bus with you when the limo breaks down.” — Oprah Winfrey

Caregiving comes with unique challenges and rewards which can be hard for friends and family to understand. If you know a caregiver, reach out to them to see if they'd like to go for a walk or for coffee. If you don't know any other caregivers, consider accessing a network group to meet some other folks who are going through some of the same things you are. There is also a growing number of support groups found online. These can be an accessible way to quickly connect to people going through similar experiences!

**Remember to make self-care a priority.**

“Today, and each day forward, try to find the fun, the laughter and joy of the day and, if nothing else, give yourself a hug. You deserve it.” – Maria Shriver

The better we care for ourselves, the more able we are to cope with the challenges that come our way. Schedule time in your week to do the things that keep you nourished. If you are struggling with this, consider asking for some support from family, friends, caregiver support programs, or your faith-based community.